Summary of the Institute of Medicine’s Reports on Cancer Survivorship

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National Academies of Science

- To serve as adviser to the nation to improve health
- To provide unbiased, evidence-based, and authoritative information and advice on health and science policy to policy-makers, professionals, leaders in every sector of society, and the public at large.
National Cancer Policy Board

- Committee of the IOM
- Established 1997 to address broad policy issues that affect cancer in the U.S.
- To recommend ways to advance the Nation's effort against cancer
- 20 members outside federal government: health care consumers, providers, and researchers in various disciplines in the sciences and humanities
Improving Quality Cancer Care

- *Ensuring Quality Care* (1999)
- *Improving Palliative Care for Cancer* (2001)
- Report on quality care in adult survivorship (forthcoming 2005)
Childhood Cancer Survivorship:
Improving Care and Quality of Life

Maria Hewitt, Susan L. Weiner and
Joseph V. Simone, Editors
Groundbreaking Report

- Comprehensive review, including expert input
- Careful peer review
- Analysis of policy implications of the hundreds of thousands of children now surviving cancer
General Features

- “Childhood” cancer is defined as cancer in one under 20 years of age
- NCI definition used: from diagnosis to death
- Method: analysis of evidence + NCPB recommendations
The Price of Success

- At least 2/3 of survivors have at least one late effect
- About 1/4 of these survivors have serious or life threatening late effects
Types of Late Effects

- Second malignancies
- Neuropsychological (learning disabilities)
- Cardiopulmonary
- Endocrine (growth and fertility)
- Psychosocial
- Musculoskeletal
- Variable in nature, time of onset and exposure
Why and When

- Cytotoxic agents, surgery and radiation given during periods of physical, neurological, psychological and social growth and development

- May emerge soon after therapy is completed or years to decades later

- Prematurely experience diseases of aging
Late Effects: Studies on Prevention and Management

- Some are preventable by dose reduction, elimination or substitution of a less toxic agent.
- The impact of some may be mitigated by early intervention.
- Close follow-up is the key to both.
Recommendations

I. Guidelines for care
Recommendations

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II. Standards for systems of follow-up care
Recommendations

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III. Awareness of late effects
Recommendations

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IV. Education
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V. Role of public service programs
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VI. Access to health care services
Recommendations

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II. Standards for systems of follow-up care
III. Awareness of late effects
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V. Role of public service programs
VI. Access to health care services
VII. Research needs
I. Follow-up Care Guidelines

**EVIDENCE**

- When report published, there were no guidelines for follow-up care

**RECOMMENDATION**

- Guidelines development is a first priority
II. Systems of Follow-up Care

**EVIDENCE**

- No widely accepted systems
- Patients often lost to follow-up, have inadequate and unsystematic follow-up
- Most provider institutions have no systematic follow-up appropriate to age of patient and nature of late effects
II. Follow-up Care Systems

**Recommendations**

- Define a minimum set of standards for follow-up care linking primary and specialty caregivers long-term.
- Ensure such systems are in place in treating institutions.
- Evaluate alternative models of care delivery.
III. Survivors’ Awareness of Late Effects

**Evidence**
- Majority of cancer survivors are unaware of their risk for late effects and the need for follow-up care
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**Evidence**
- Majority of cancer survivors are unaware of their risk for late effects and the need for follow-up care

**Recommendations**
- Improve awareness of late effects and their implications to long-term health among childhood cancer survivors and their families
IV. Professional Training

**EVIDENCE**

- Too few advanced practice nurses to staff follow-up clinics (usually responsible)
- Oncologists and primary care docs often lack knowledge of late effects
- Cursory coverage of issues in medical texts
- 1 in 300 ambulatory care visits by children is cancer related; increase is inevitable
IV. Professional Training

**Recommendation**

- Improve professional education and training about late effects of childhood cancer and their management for both specialty and primary care providers.
V. Service Programs - Public

EVIDENCE

- Many problems of cancer survivors are shared by children and adults with other chronic/disabling diseases/conditions
- Coordination among programs in DHHS, DOE and at state is poor
  - Eligibility, covered services differ
- No program has the specific mission to address needs of childhood cancer survivors
V. Public Programs

**Recommendation**

- Health Resources and Services Administration & Child Health Bureau + partners should be supported to implement Health People 2010 goals for Children with Special Care Needs, including a national communication strategy, capacity building, setting standards, and establishing accountability.

- Dept. of Ed. has important service role.
VI. Access to Health Care Services

*Evidence*

- Insurance often does not cover cancer survivors and their special health and service needs
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**Evidence**
- Insurance often does not cover cancer survivors and their special health and service needs

**Recommendation**
- Federal, state & private efforts needed to optimize survivors’ access to resources and delivery systems through health insurance reforms and public safety net programs
VII. Research Needed

**EVIDENCE**

- Continued, systematic follow-up of cohorts of survivors can reveal the extent of late effects and suggest prevention and amelioration strategies
  - CCSS & some cancer centers yielding vital data
- Treatment modifications can reduce late effects
- Little work done on interventions
VII. Research

RECOMMENDATIONS

- Funding organizations should increase support to develop strategies to prevent or ameliorate late effects
- Studies needed on prevalence and etiology, treatment modifications, interventions, and improvements in overall quality of care
SO - WHO IS RESPONSIBLE?
I. Guidelines for follow-up care

**RECOMMENDATION**

- Guidelines development is a first priority

www.childrensoncologygroup.org
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**RECOMMENDATION**

- Guidelines development is a first priority

**WHO?**

- COG Late Effects Committee developed the guidelines!

www.childrensoncologygroup.org
II. Standards for systems of follow-up care

**RECOMMENDATION**

- Define minimum standards to link primary and specialty caregivers
- Ensure such systems in place in treating institutions
- Evaluate alternative models of care delivery
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**WHO?**

- NCI should convene experts
- Professional societies should endorse
- COG institutions should ensure services available at institutions
- State cancer control plans for services
- Demonstration & eval. of programs through HRSA
III. Awareness of late effects

RECOMMENDATION

- Improve survivors’ and families awareness of late effects and long term health implications
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**RECOMMENDATION**

- Improve survivors’ and families’ awareness of late effects and long term health implications

**WHO?**

- Clinicians: begin at diagnosis
- NCI and nonprofit health educator and advocacy groups
IV. Professional education

Recommendation

- Improve education and training about late effects and management for specialty and primary care providers
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**Recommendation**
- Improve education and training about late effects and management for specialty and primary care providers

**WHO?**
- Professional societies
- Primary care programs
- Onc training programs
- Onc board exams
- NCI website
- Interdisciplinary mtgs
V. Strengthen public service programs

RECOMMENDATION

- HRSA & Matl/Child Health Bureau & other DHHS prgms should be supported to implement Health People 2010 goals for Children with Special Care Needs: a national communication strategy, capacity building, setting standards, and establishing accountability.
V. Strengthen public service programs

**RECOMMENDATION**

- HRSA & Matl/Child Health Bureau & other DHHS prgms should be supported to implement Health People 2010 goals for Children with Special Care Needs: a national communication strategy, capacity building, setting standards, and establishing accountability

**WHO?**

- DHSS, HRSA
- CMS, Medicaid
- S-CHIP Programs
- Dept.Ed Early Intervention
- Dept.Ed Special Ed
VI. Access to health care services

**Recommendation**

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**WHO?**
- Federal & state legislation on specific issues
- Private & public insurers to provide appropriate services and range of providers
VII. Research

**RECOMMENDATION**

- Increase support to prevent or ameliorate late effects
- Research prevalence, etiology, treatment modifications, interventions, and improvements in overall quality of care
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**WHO?**

- NCI
  - CCSS
  - Health outcomes
- COG f-up for clin trs
- Other NIH institutes
- Private funders, e.g., ACS
Summary

- NCI needs to take coordinating role
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- Late effects are a moving target
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- Longitudinal research and follow-up are vital to preserve our investment
Summary

- NCI needs to take coordinating role
- Late effects are a moving target
- Longitudinal research and follow-up are vital to preserve our investment
- Information dissemination to professionals, survivors and families is essential to improving and preserving our children’s lives
SOCIETAL AND PROFESSIONAL COMMUNITY RESPONSIBILITY
Report available at

Institute of Medicine Website

http://www.iom.edu